Indigenous people living with cancer: developing a mobile health application for improving their psychological well-being

Emergent Research Forum Paper

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Abstract

Poor cancer outcomes experienced by Indigenous Australians result from advanced cancer stages at diagnosis, poorer uptake of and adherence to treatments, higher levels of co-morbidity, and poorer access to inclusive and culturally appropriate care compared with non-Indigenous Australians. Socio-economics and social support can mitigate these problems. Technology-based interventions hold considerable promise for enhancing social support. This paper asks what are the key features of a mobile health application designed to improve the social support and consequently psychological well-being of Indigenous Australians living with cancer? To answer this question, a comprehensive literature review of studies conducted in information systems and health disciplines has been undertaken and a theoretical model is proposed. This study contributes to the existing knowledge base through the development of a new theoretical model and the introduction of the features of a mobile health application that may have a positive impact among Indigenous Australian cancer patients' psychological well-being.

Keywords

Indigenous Australians, cancer affected people, mobile application

Introduction

Poorer cancer outcomes experienced by Indigenous Australians result from more advanced cancer stages at diagnosis, poorer uptake of and adherence to treatments, higher levels of co-morbidity, and poorer access to inclusive and culturally appropriate care compared with non-Indigenous Australians (Garvey et al., 2012). A diagnosis of cancer is a life-changing event that can take a great toll on a person's psychological well-being. Many people living with cancer suffer from psychological problems and as a result have difficulty relating to their families and communities. Social support in terms of emotional support, network support, esteem support, and information support can mitigate these problems. Emotional support includes expressions of caring, sympathy, listening, understanding, empathy, or encouragement; network support refers to expressions of companionship and connection; tangible or instrumental support is the provision of needed goods and services; and informational support includes guidance, advice, facts, stories of personal experiences, or referrals to other sources of information.

Technology-based interventions hold promise for enhancing those forms of social support and for developing a sense of connectedness among cancer sufferers (Erfani et al., 2016a). The aim of this study –

which is a part of a larger study – is to introduce the features of a culturally appropriate smartphone application (app) to facilitate the care needs for Indigenous Australians living with cancer. Use of the proposed mobile health app will assist in managing their informational, emotional, and psychological needs and enable them to connect with other Indigenous and non-Indigenous cancer patients for mutual support to enhance their psychological well-being.

Background and significance

Cancer is a major cause of morbidity and mortality in Australia. Among Indigenous Australians, between 2009 and 2013, 1,264 males and 1,153 females died from cancer (AIHW 2016). The chance of an Indigenous Australian surviving at least five years following a cancer diagnosis was just 43%, and the number of Indigenous Australians known to be living with cancer at the end of 2010 was 2,558 (AIHW 2016). There has been little consideration of the experiences of cancer among Indigenous Australians, and there is a paucity of data comparing cancer outcomes for Indigenous Australians with those of non-Indigenous Australians. Informed cancer patients can be more empowered and active in their treatment and recovery (Erfani et al., 2013). The world-wide web (WWW) has become an increasingly important part of health care and support services. For instance, Web 1.0, or the static web (e.g. websites and e-newsletters), gives cancer patients access to quality cancer-related information published by reputable health organizations. Web 2.0 further enables patients to collaboratively create cancer-related content, develop two-way communication, make sense of information, and exchange emotional support (Erfani and Abedin, 2014). A recent study showed that the use of web-based support interventions helped cancer patients obtain more social support and improved the social connectedness. The cancer patients also learned healthier behaviors that led to better psychological well-being and improved ability to cope with cancer outcomes (Erfani et al., 2016b).

Psychological well-being is defined in terms of autonomy, personal growth, self-acceptance, life purpose, environmental mastery, and positive relatedness (Winefield et al., 2012). Autonomy means being able to resist social pressures; personal growth refers to feelings of continued development; self-acceptance means holding positive attitudes toward oneself; life purpose is a sense of direction in life; environmental mastery is about feeling competent in creating context suitable to personal needs; and positive relatedness is the extent to which one forms satisfying relationships with others. Psychological well-being can also be conceptualized as feeling happy, capable, well supported, and satisfied with life (Moyer et al., 2014).

Web 3.0, or the mobile web, combines tools and content from Web 1.0 and Web 2.0 platforms in one space such as a smartphone or tablet app. Growing smartphone ownership has led to an increase in the number of health-related mobile apps. However, our analysis of the main online app stores, iTunes and Google Play, showed that while dedicated apps for cancer care are available, there are not still any apps specifically targeted at Indigenous cancer patients. Cultural differences and language remain barriers to accessing health care and support services (Garvey et al., 2012). Accordingly, developing a culturally appropriate mobile health app for Indigenous Australians with cancer is crucial and timely for the provision of appropriate supportive care. The study in this paper therefore seeks to answer the following research question: What are the key features needed for a mobile health app designed to improve the psychological well-being of Indigenous Australians living with cancer?

Theoretical underpinnings and research hypotheses

The proposed intervention and mobile health app are inspired by recent research conducted in Australia (Erfani et al., 2016a). This study will use a multi-theory perspective, including belongingness theory, sociocultural theory, social cognitive theory and self-determination theory to guide the design. The mobile health app will be designed and pilot-tested in the second phase of the study (to be presented in a future publication). The intervention will have four components, as outlined in the following sections.

1. Building connections (peer and mentor talk): This component will enable Indigenous Australians living with cancer to create an online profile containing their demographic information as well as information about their culture, language group, community attachment, and the type of cancer they have. The connection component will have two features: peer talk and mentor talk. (i) *Peer talk*: This feature allows patients to connect with others who are going through similar experiences, develop discussions and social relationships, and enlist social support emotional support from people with similar

health concerns.(ii) *Mentor talk*: This feature enables patients to communicate with and receive support from a lead primary care provider who can assist with discipline-specific questions.

Studies have shown that support resources that provide peer-to-peer support can help people living with cancer to develop a sense of belongingness (network support) and improve their adherence to treatment regimens (Erfani et al., 2016a). Belongingness theory (Baumeister and Leary, 1995) posits similarly that individuals who develop supportive relationships experience a sense of belonging and consequently greater psychological well-being. Studies have shown a positive correlation between integration in peer support cancer interventions, sense of belongingness and experiencing well-being (Agosto, 2012; Erfani et al., 2016a). This evidence led us to propose these hypotheses:

H1: A positive relationship exists between using building connections component and emotional support and H2: Emotional social support has a positive impact on the psychological well-being of Indigenous Australians living with cancer.

2. Learning center: This component will include two features: passive learning and active learning.

Passive learning: The purpose of this feature is to improve users' knowledge. To develop content for the passive learning feature, information on cancer care needs will be extracted from the scientific literature and will be refined in focus groups with Indigenous Australians who are living with cancer. These needs are likely to include: developing effective and meaningful communication skills with health care providers and friends; managing negative emotions and symptoms such as anger, fear and fatigue; eating well and maintaining healthy diets. Health care professionals and experts in cancer care needs will be consulted to provide educational content that will address the needs and be presented in the learning center.

Active learning: This feature allows the presentation of role model narratives. This feature, which is similar to an online discussion board, enables patients to post questions and reply to other posts.

This component enables users to receive informational support through guidance, and stories of personal experiences. According to sociocultural theory, learning is a social process that occurs through conducting or observing interactions (Lantolf, 1994). Successful learning involves moving from object and intermediate regulation to self-regulation. Object regulation is the stage where learners start to learn by observing an object in a social environment. In the intermediate regulation stage, learners learn by obtaining assistance and receiving feedback from peers or mentors. In the self-regulation stage, learners become competent enough to perform independently (Lantolf, 1994). Previous studies showed that breast cancer patients using the Comprehensive Health Enhancement Support System learned how to take charge of their treatment, and ultimately experienced better psychological well-being (Gustafson et al., 1994). Based on this evidence, we developed these hypotheses: *H3: A positive relationship exists between using learning center component and informational support and H4: Informational support has a positive impact on the psychological well-being of Indigenous Australians living with cancer.*

3. Goal setting: This component allows participants to be supported through the adoption of goal-oriented care approaches. Patients and providers will collaboratively identify goals (e.g. pain management or weight management), make an action plan each week, report and monitor their progress, and receive feedback. This component facilitates esteem support through expressions of positive communication behaviors for support seekers. Self-management outcomes are thought to benefit patients' health primarily through changes in health behaviors – by helping patients to develop the confidence to engage in tasks that help them better manage their health. Self-management is an important predictor of experiencing better psychological well-being. Self-efficacy, a central variable in social cognitive theory, refers to people's judgments of their capabilities to perform certain actions (Bandura, 1997). Bandura argues that self-efficacy influences many aspects of individual behaviors, such as the acquisition of new behaviors, inhibition of existing behaviors, and disinhibition of behaviors (Bandura, 1997; Stretcher, et al., 1986). Based on these ideas, we developed the following hypotheses: *H5: A positive relationship exists between using goal setting component and Esteem support and H6: Esteem support has a positive impact on the psychological well-being of Indigenous Australians living with cancer.*

4. Motivation and relaxation: This component contains a list of coping strategies, inspirational quotes, and motivational phrases and images designed to encourage Indigenous Australians living with cancer. Self-determination theory holds that people need to feel competent (Deci and Ryan, 2000). The support and social resources that can address these needs are associated with the development of positive

psychological outcomes (Deci and Ryan, 2000). This component will provide tips for relaxation. *H7: A positive relationship exists between using Motivation and relaxation component and Network support and H8: Network support has a positive impact on the psychological well-being of Indigenous Australians living with cancer*. The following theoretical framework (shown in Figure 1) explains how and in what ways using the proposed mobile health app can have a positive impact on the psychological well-being of Indigenous Australians living with cancer:

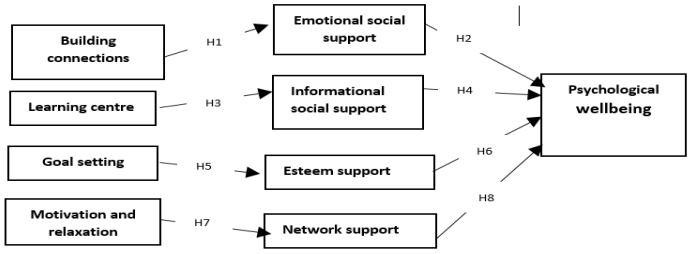

Figure 1: The use of mobile health app and psychological well-being

Research plan and methods

This research will use a mixed-methods approach to combine both qualitative and quantitative data.

Phase one: In the exploratory phase, face-to-face interviews will be conducted with Indigenous Australians living with cancer to explore their unmet cancer care needs (informational, emotional, psychological, and social). The purpose of this phase is to add components to the proposed theoretical model. The hypotheses and theoretical model will be updated based on results of the exploratory phase. Probability sampling (using a cluster sampling technique) will be applied in this phase. Participants will be recruited from major public hospitals and support services in the Northern Territory, Queensland and New South Wales. The sample size for interviews will be decided by the saturation point of the data. Data collected in this phase will be analyzed using thematic analysis to collect the candidate themes and identify relationships between them (Vaismoradi, et al., 2013).

Phase two: In the confirmatory data analysis phase, we will verify the findings from phase 1, with quantitative data. These analyses will provide insight into the relative rank-ordered cancer care needs and preferences for the mobile health app features. Indigenous Australians living with cancer who attend hospitals for treatment will be informed about the study and invited to complete the questionnaire.

Phase three: In this third phase, health care professionals (e.g. cancer specialists, psychologists, and social workers) will be invited to our research. Focus groups will be conducted to get their opinion on how to address the identified cancer care needs (e.g. managing negative emotions).

Phase four: Based on findings from the previous three phases, the mobile health app will be developed and pilot-tested with actual participants. We will apply a pre-post design approach to measure the effect of using the proposed mobile health app on the psychological well-being of Indigenous Australians living with cancer.

Discussion, theoretical and empirical contributions

The proposed mobile health app will provide educational support and tools for management of cancer for Indigenous Australians. The app will have a number of features that provide information about living with cancer, symptoms and treatments, raise awareness and increase knowledge. The mobile app will enhance and encourage users psychological wellbeing; a critical element to improve cancer patients adherence to treatments and overall health outcomes. It will also support Indigenous Australians to allay their fears about cancer and enhancing users sense of connectedness to other Indigenous cancer patients and health care providers, family and friends. The mobile health app will collect data that are important for informing health policies, decision-making, and service planning. The profile feature in the mobile health app will provide important information about the types of cancers affecting Indigenous Australians, and the mentor talk component will reveal the concerns of Indigenous Australians, thereby contributing to the evidence base to inform health policy, program, and service delivery. The active learning component

addresses two important areas of need. The first area of need is in the domain of online health-related community analytics where developers of web-based health related services and networks require information about users as well as information about how the service can be used to optimally provide value for patients. The second area of need is in ecological momentary assessment where health care researchers will be collecting data from research subjects in their natural environments. This research will make significant theoretical and empirical contributions to our understanding of the benefits of technology interventions and mobile health apps in cancer care for Indigenous Australians. This research has also broader practical implications for Australian health care providers. It will produce new data about Indigenous Australians living with cancer, which can be used to promote online health-related networks and to improve the long term care of people living with cancer.

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